Citation:
Grassi, L and Fujisawa, D and Odyio, P and Asuzu, C and Ashley, L and Bultz, B and Travado, L and Fielding, R (2016) Disparities in psychosocial cancer care: a report from the International Federation of Psycho-oncology Societies. Psychooncology, 25 (10). pp. 1127-1136. ISSN 1099-1611 DOI: https://doi.org/10.1002/pon.4228

Link to Leeds Beckett Repository record:
https://eprints.leedsbeckett.ac.uk/id/eprint/3159/

Document Version:
Article (Accepted Version)

Creative Commons: Attribution-Noncommercial 4.0

The aim of the Leeds Beckett Repository is to provide open access to our research, as required by funder policies and permitted by publishers and copyright law.

The Leeds Beckett repository holds a wide range of publications, each of which has been checked for copyright and the relevant embargo period has been applied by the Research Services team.

We operate on a standard take-down policy. If you are the author or publisher of an output and you would like it removed from the repository, please contact us and we will investigate on a case-by-case basis.

Each thesis in the repository has been cleared where necessary by the author for third party copyright. If you would like a thesis to be removed from the repository or believe there is an issue with copyright, please contact us on openaccess@leedsbeckett.ac.uk and we will investigate on a case-by-case basis.

Disparities in psychosocial cancer care:

A report from the International Federation of Psycho-Oncology Societies

Luigi Grassi[1] *, Daisuke Fujisawa[2], Philip Odyio,[3] Chioma Asuzu,[4]

Laura Ashley,[5] Barry Bultz,[6] Luzia Travado[7,] Richard Fielding,[8] on behalf of the IPOS

Federation of Psycho-Oncology Societies' co-authors [a]

1. Institute of Psychiatry, Department of Biomedical and Specialty Surgical Sciences, University of Ferrara, Ferrara, Italy (e-mail: luigi.grassi@unife.it) Tel +39 0532236409 Fax +390532212240
2. Department of Neuropsychiatry and Palliative Care Center Keio University School of Medicine, Tokyo, Japan (e-mail: dai_fujisawa@yahoo.co.jp)
3. Faraja Cancer Support Trust and Daystar University, Nairobi, Kenya (e-mail: phillip@farajacancersupport.org)
4. Department of Counselling and Human development Studies; Department Radiation Oncology, University of Ibadan, Ibadan, Nigeria (e-mail: chiomasuzu20@yahoo.com)
5. Leeds Beckett University, Faculty of Health & Social Sciences, Calverley Building, Leeds, UK (e-mail: l.j.ashley@leedsbeckett.ac.uk)
6. Department of Psychosocial and Rehabilitation Oncology, Tom Baker Cancer Centre, and Division of Psychosocial Oncology , Cumming School of Medicine, University of Calgary, Calgary, Canada (e-mail: bdbultz@ucalgary.ca)
7. Psycho-Oncology, Champalimaud Clinical Centre, Lisbon, Portugal (e-mail: luzia.travado@fundacaochampalimaud.pt)
8. The University of Hong Kong, School of Public Health, Centre for Psycho-Oncological Research and Training, Hong Kong, HK (e:mail fielding@hku.hk)

---

[a] Co-authors of the present manuscript are:

Judith Alder (judithalder1@gmail.com), Switzerland
Elisabeth Andtritsch (Elisabeth.Andritsch@klinikum-graz.at), Austria
Antonio Barbosa (abarbosa@netcabo.pt), Portugal
Joan Bottorff (joan.bottorff@ubc.ca), Canada
Giedre Bulotiene (giedre.bulotiene@vuoi.lt), Lithuania
Phillys Butow (phyllisb@psych.usyd.edu.au), Australia
Miri Cohen (mcohen2@univ.haifa.ac.il), Israel
Anna Costantini (annacostantini@alice.it), Italy
Sara Dauchy (Sarah.DAUCHY@gustaveroussy.fr), France
Csaba L. Dégi (csabadegi@gmail.com), Romania
Jurama Ribeiro de Oliveira (presidente@sbpo.org.br), Brazil
Krystyna de Walden-Galuszko (galuszko@ptpo.org.pl), Poland
Haryana Dhillon (haryana.dhillon@sydney.edu.au), Australia
Chun-Kai Fang (chunkai.fang0415@gmail.com), Taiwan
Michelle Cororve Fingeret (MCFinger@mdanderson.org), USA
Francisco Luis Gil (fgil@iconcologia.net), Spain
Patrik Göransson (ordforande@swedpos.se), Sweden
Josette Hoekstra Weebers (.Hoekstra@iknl.nl), The Netherlands
Clare Louise Manicom (Clare.Manicom@cancercare.co.za), South Africa
Deborah McLeod (DeborahL.McLeod@cdha.nshealth.ca), Canada
Lúcia M. Silva Monteiro (lmonteiro@ipolisboa.min-saude.pt), Portugal
Jong-Heun Kim (psy@ncc.re.kr), Korea
Hazel Neser, (hazel.neser@otago.ac.nz), New Zealand
Eisuke Matsushima (em.lppm@tmd.ac.jp), Japan
William F. Pirl (WPIRL@PARTNERS.ORG), USA
Melanie Price (melanie.price@sydney.edu.au), Australia
Laura Monica Radu (ml2radu@yahoo.com), Romania
Thomas Schopperth, (tschopperth@krebsgesellschaft-rlp.de), Germany
Andrea Schumacher (Andrea.Schumacher@ukmuenster.de), Germany
Anja Simonič (anja.simonic@klinika-golnik.si), Slovenia
Lili Tang (tanglili2005@hotmail.com), China

*** Corresponding Author:**
Luigi Grassi, M.D.
Institute of Psychiatry
Department of Biomedical and Specialty Surgical Sciences
University of Ferrara, Ferrara, Italy
e-mail: luigi.grassi@unife.it
Tel +39 0532236409 Fax +390532212240

Keywords: cancer, oncology, psycho-oncology, disparities, psychosocial care, Federation Psycho-Oncology Societies

Abstract

Background: The aim of the study was to understand the characteristics of the International Federation of Psycho-Oncology Societies (FPOS) and possible disparities in providing psychosocial care in countries where psycho-oncology societies exist.

Method: A survey was conducted among 29 leaders of 28 countries represented within the FPOS by using a questionnaire covering (i) characteristics of the society; (ii) characteristics of the national health care system (NHS); (iii) level of implementation of psycho-oncology and (iv) main problems of psycho-oncology in the country.

Results: Twenty-six (90%) FPOS returned the questionnaires. One-third reported to have links with and support from their government, while almost all had links with other scientific societies. FPOS varied in their composition of members' professions. Psychosocial care provision was covered by state-funded health services in a minority of countries. Disparities between countries arose from different causes and were problematic in some parts of the world (e.g. Africa, SE Asia). Elsewhere (e.g. Southern Europe, Eastern Europe), austerity policies were reportedly responsible for resource shortages with negative consequences on psychosocial cancer care. Half of FPOS rated themselves to be integrated into mainstream provision of care, although lack of funding was the most common complain.

Conclusion: The development and implementation of psycho-oncology is fragmented and undeveloped, particularly in some parts of the world. More effort is needed at national level by strong coalitions with oncology societies, better national research initiatives, cancer plans and patient advocacy, as well as by stronger partnership with international organizations (e.g. WHO, UICC).

Introduction

Cancer is a worldwide problem and globally attention has been directed by national governmental organizations and health institutions to emphasize policies of prevention and screening, treatment, follow-up, and palliative care [1,2,3]. However, internationally, social inequalities persist in terms of cancer care, especially, but not only, in socioeconomically disadvantaged groups, under-served communities and in developing countries. [4] As regards psychosocial care at least 30% of cancer patients report psychosocial distress and mental disorders [5] and a even higher percentage report unrecognized psychosocial needs or untreated psychosocial disorders as a consequence of cancer at some point during the cancer trajectory. [6,7] For example, while point prevalence rates of 40% are commonly reported, only in around one-in-six [8] to one-in-twelve [9)] women with breast cancer do these problems persist, sometimes over many years, often linked to unresolved symptoms such as pain [10]. The literature consistently indicates that persistent psychosocial conditions have extremely negative consequences for the patients, including poorer quality of life [10] and shorter survival [11,12]

Consequently there is an urgent need to ensure appropriate psychosocial care is available in cancer settings. However, as with other cancer services, inequalities exist. As reported by Koch [13], although a large number of evidence-based studies have demonstrated the benefit from structured psychosocial care services in oncology, with a growing consensus on the mandatory integration of psychosocial care into the routine care of cancer patients [14], there is an evident lack of precise and comprehensive information about psycho-oncology services within the national health-care systems of different countries. This lack of information pertains to several aspects of care, such as if and where psychosocial services in different health-care provision areas of cancer care are available (e.g. inpatient and outpatient services, rehabilitation, and palliative care), what type of professionals of different disciplines (and their qualifications) work in psychosocial oncology services, and how much these services are integrated in the existent oncological services. According to Keller et al. [15], some of the main indicators of psychosocial oncology are not followed by most of the countries where the objectives and the topics of psychosocial health-care research for cancer patients, the study of structural conditions of psycho-oncology services and of psycho-oncology interventions under routine conditions, and quality assurance are lacking.

In Europe, a recent survey conducted under the European Partnership on Action Against Cancer [EPAAC] and involving 27 representatives of European countries, showed that only eight (30%) reported having nationally recommended psychosocial oncology care (PSOC) clinical guidelines, with ten (37%) having specific budgets for PSOC, and six (22%) having an official certification for PSOC education. [16]

The situation is even more fragmented and diverse when considered internationally. In one of the first surveys conducted by interviewing 45 psycho-oncology experts from 38 countries [17], it was shown that psychosocial oncology was not fully integrated into oncological care in the majority of the countries from which experts responded. In at least one-third of the countries psychosocial oncology was not widely known or only accepted within educated and well-informed subgroups, and in the same percentage there was a lack of knowledge about the need or benefits psychosocial care. A series of different barriers were identified, including financial constraints, that were mentioned by almost all of the experts who responded, poor transfer of psychosocial research results into clinical practice, lack of knowledge and acceptance by medical professionals, stigmatization from being labeled as having a psychiatric problem or as being unable to cope with the disease, poor understanding of psychosocial support by cancer patients, and reticent trends towards disclosure of cancer diagnosis were slow, were still as problems in some countries.

Where Psycho-Oncology Societies (POS) have existed for many years, however, the situation of psychosocial oncology care in those countries is expected to be and should be more structured and defined. The mission of POS in fact is usually not only to promote psychosocial care of cancer patients and their families through the development of standards, practice guidelines, and service integration strategies, but also to foster interprofessional and political (e.g. administrators, policy makers and other stakeholders) collaboration in psychosocial oncology care. When the IPOS Federation of Psycho-Oncology Societies (FPOS) was founded in 2008, [18] the opportunity has been offered to begin to explore this specific area and to understand the situation in the countries where a scientific society exists is more advanced in terms of care and integration within the national health system. In a preliminary study carried out within the FPOS, however, the impact of scientific societies was found to be not determining, with only a few countries (mainly in Europe), resulting to have national cancer plans underlining (or at least mentioning) the mandatory role of psychosocial care in oncology. In contrast, in many others, especially, but not exclusively, in developing

nations, psychosocial oncology is either still not established or not completely established, or not an integral part of cancer care or not specifically offered except within the context of more, general psychological support, even if an established POS was operating [19].
Given the need to better understand these data and the main problems causing possible disparities in psychosocial oncology care in countries were POS are active, the present study, as part of a shared program within the FPOS, aimed at examining the characteristics of the POS represented within the Federation, the possible differences in the health care system organization of the respective countries, and the main problems of the single POS in disseminating psychosocial care in cancer settings in their own countries.

Methods

At the time of the study the Federation consisted of 28 POS in 29 countries worldwide (Fig 1). For the aims of this survey the methodology of other similar investigations [17,18,19] was followed, by using a short questionnaires with mainly open questions. The questionnaire of employed in this survey was developed on an agreement basis within the representatives of the FPOS members at a specific meeting held at the IPOS Congress in Rotterdam in 2012. At the meeting the representative members of the FPOS unanimously decided to investigate, in his phase, some specific areas in a semi-structured way, leaving for the future a further exploration with a more traditional multi-item Likert-scale questionnaire, according to the descriptive data that would be emerged in this study. Since the main aim of the questionnaire were to assess the profile of each society, the criteria for the developmental level of palliative care service from the Global Atlas of Palliative Care [20] was adopted by replacing the word palliative care by psychosocial oncology care. The major areas covered by the questionnaire are reported in Appendix 1, in which six levels of psychosocial care organization is indicated, as reached on a consensus basis within the above-mentioned FPOS meeting. The president (or a designated member) of each POS was then officially approached and the questionnaire emailed in January 2014.
By following what done in similar studies [18,19], since the responses regarded qualitative data, only descriptive statistics were used to analyze the questionnaire.

Results

Of 29 POS belonging to the Federation in 2014 and representing 28 countries (with Portugal having 2 national POS), data were available for 25 (89.5%).

Members and type of profession

The total membership of the 26 POS was 7,532 (minimum 15, Slovenia, founded in 2011, maximum 1,683, Japan, founded in 1986), of whom were 2,552 in Europe, 2,355 in East Asia (organized in the East Asian Psycho-Oncology Network, EAPON, now called Asian Pacific Psycho-Oncology network - APPON), 1,257 in Australia/New Zealand, 1,080 in North America, 162 in Middle East, and 100 in Africa (Table 1).

Regarding the primary profession (Fig 2), 30% of the members were psychologists (n=2,317), 29% physicians (n=788 psychiatrists, n=1410 other physicians), 12.5% nurses (n=947, of whom 580 were specialized cancer or palliative care nurses and 367 registered nurses), 7.8% social workers (n=590), approximately 3% patient/family members (n=50), pastoral care persons (n=40), rehabilitators (n=40) and 2% full-time researchers (n=146). About 16% members belong to other professions (including physical, sex, or occupational therapists; pharmacists) or categories (including students, administrators, and other allied health groups).

There were differences by continents, with a higher ratio of physicians (including psychiatrists) (45-70%) with respect to psychologists (13-28%) and nurses (15-18%) in Eastern Asian POS; a higher ratio of psychologists (35-40%) and social workers (25-30%) with respect to physicians (including psychiatrists) (20%) in North America and in Australia /New Zealand; and a higher ratio of psychologists (30-90%) in comparison with physicians (including psychiatrists) (30-40%) in European POS, with the highest percentage of psychologists being in the Polish and Spanish (80%), and South American POS (90%).

Health Organization system

There were major differences among countries regarding the structure and organization of health systems and provision of psychosocial care. In some Northern American and Asian countries, including Canada, Japan, and Taiwan) universal-coverage national health systems fund cancer care, including psychosocial aspects; in others, including the USA and China when government-funded health system or private insurance does not completely cover all citizens, or co-payment is required, patient advocacy organizations and professional

organizations in some instances provide psychosocial care having incorporated these services as part of comprehensive cancer care. Otherwise, access may be lacking.

In several European countries government-based insurance systems, the National Health Service (UK) or the national universal healthcare insurance coverage, (for example France and Germany) includes psychosocial care, with widespread acknowledgment of the importance of psychosocial care throughout the cancer continuum and psycho-oncologists integrated in supportive care teams or with strong links with supportive care professionals. In other European countries, insufficient insurance coverage for psychological treatment and psychosocial care is reported, in part because of the nature of the health care system. In a growing number of European countries, economic austerity policies are reducing health care spending, forcing cuts to all but most basic services, impacting psycho-oncology and mental health in general.

Elsewhere, for example in African and some SE Asian countries, the availability of appropriate primary cancer treatment itself is a problem, with limited access to first-line therapies, such as surgery, radiotherapy and chemotherapy, significant urban-rural inequalities and economic and geographic barriers and rudimentary National health insurance schemes. These problems mean access is mostly only available to a small, often urban-based elite portion of the population. This has been reported to contribute to delayed cancer diagnosis in numerous patients with negative consequences in terms of prognosis and outcome, particularly where chronic disease care has to compete with other care demands such as maternal and neonatal care, communicable diseases and violence. Understandably this creates problems in screening, early diagnosis and treatment of cancers. In some places, disruption of and even targeting of health services by political instability, war or insurgency prohibits even the most basic care.

National variation in psycho-oncology service development

The situation of psychosocial care in oncology, according to the 6 possible levels of organization (see Appendix 1), as represented in the country, is detailed in Table 1. Overall 23% of the POS indicated in their own country embodied isolated care provision of psychosocial oncology (Level 3a); 20% indicated that a generalized care provision (Level 3b); 46% were in a more advanced state (Level 4a), having preliminary integration into mainstream service; only 11% indicated an advanced integration into mainstream service

provision (Level 4b). Globally, 50% of POS in Europe, Asia and Australia/New Zealand referred to their psycho-oncology situation as level 3 and 50% as Level 4, while 100% in North America rated it as Level 4. More problems were found in South America and Africa where the only societies existing there rated psycho-oncology as isolated (Level 3a). In Africa, one country (that had not formally a society, but in the process of doing that at the time of the study) rated the situation as in progress with possible capacity of building activities, though no service has yet been established (Level 2).

Main reported problems

Several types of problems were however reported by the POS participating in the survey (Table 3). All POS underlined a lack of financial support for psycho-oncology services. Some societies (mainly in Eastern and Southern Europe, Africa and South America) also indicated that the austerity had worsened the situation with several negative effects, on, for example, stalling the implementation of National Cancer Plans (psychosocial care integrated into cancer care) and not being considered essential to service implementation (e.g. Italy). Several societies (e.g. Netherlands) reported the need for more scientific evidence for the cost-effectiveness of various psychosocial interventions for the patient and for society in order to increase the willingness of medical specialists to refer, of health insurance companies to reimburse and of the political world to put psychosocial care high on the agenda.

Discussion

In this study, coordinated under the aegis of IPOS, we reported data from 26 psycho-oncology societies, representing 25 countries in the world, that are members of the international Federation of POS, representing several countries in the world, with additional input from APPON members.

As an initial finding, significant differences were found between the organization of the POS, in part reflecting the differences in the health organizational systems of the countries that were part of the survey. It is in fact difficult to compare POS that have a huge number of members and seem extremely well developed with more limited societies struggling with needs for recognition within their country and health systems or where the numbers of active psycho-oncology workers amount to only a handful. Also the role of professionals is quite

different, with some societies consisting almost completely of psychologists, others having a high percentage of physicians, mainly but not only psychiatrists, and others involving also nurses and social workers. A general trend was apparent confirming what reported in a previous Federation survey [19], specifically that of POS are formally linked to institutional bodies (e.g. Ministry of health, central governmental institutions) with psycho-oncology fully recognized in National Cancer Plans (NCPs).

In terms of implementation of psycho-oncology and self-evaluation of their status, only a minority of POS representatives (1 in Europe, 1 in Asia, 1 in Australia) reported in their own country an advanced integration into mainstream service provision, with psychosocial oncology care available in a wide range of locations, a comprehensive provision of care by multiple service providers, a substantial impact of psychosocial oncology care upon policy, an unrestricted availability of multiple aspects of psychosocial oncology care, a broad awareness of psychosocial oncology care on the part of health professionals, local communities and society in general; as well as a development of recognized education centers and academic links forged with universities.in particular upon public health policy. The situation in Europe, in particular, seemed to be fragmented in countries were POS have been long established, with more problems in Southern and Eastern European than Northern European countries. In those countries, because of restriction of investments and irrespective of the recognition or not of psychosocial oncology within the national cancer plans, policy-making bodies seemed to have gradually transformed a human right, as it is for psychosocial care, to a luxury not constituting an essential component of care. These findings confirm what reported by a recent European study that, although it did not take into account if POS were or not were active [18], showed that only 30% reported as having nationally recommended psychosocial oncology care clinical guidelines, and 37% as having specific budgets for these guidelines. Significant disparities were also reported in the only two psycho-oncology societies in Africa, one of which is formalized as a POS and the other which is in the process.

Several challenges and problems were identified by the participating POS in this survey, again these varied according to local circumstances. A number of POS identified the paucity of funding for clinical care as a major problem. Governments and insurers almost everywhere are attempting to reduce health care expenditures using austerity policies, economic exigencies and privatization to justify this, in some cases for purely ideological reasons. These factors have seemingly limited the growth and development of psycho-oncology care for

cancer patients or reduced their capacity were they exist. Where disposable incomes are limited and out-of-pocket or co-payment is required, many patients are unwilling to seek or cannot afford professional help that does not directly serve curative functions. There has also been an overall decline in research funding awarded to psycho-oncology, with only small, often declining percentage of the budgets of cancer societies or national programs allocated to psychosocial oncology research. One POS cited the need for stronger research evidence to clarify the benefits of some psycho-oncology interventions in cost-effectiveness terms as well as outcomes (e.g. 21), something that will prove increasingly difficult with financial restrictions.

On these figures, in the future of the IPOS Federation new significant obligations should be added in its mission, as repeatedly stressed elsewhere [22,23,24]. It is necessary to help those countries which, although active within their national POS, are still not able to liaise with governmental institutions in order to have psychosocial oncology standards of care in national cancer plans. Also, besides creating opportunities for training and the provision of support in drafting and implementation of POS where they do not exist, it seems to be mandatory the development of more effective policies. The role of IPOS and other organization supporting IPOS, such as the World Health Organization (WHO) and the Union for International Cancer Control (UICC), should be considered strategic in this. The WHO for example has strongly supported palliative care as a fundamental area to health and a basic human right, by clearly and unambiguously recognizing the obligation of all countries to make sure no one needlessly suffers from pain and other debilitating symptoms [25,26]. It is mandatory to apply and to extend these aims to whole trajectory of cancer care, where debilitating symptoms, including psychosocial distress and the manifold forms of spiritual suffering and mental disorders should be also recognized as a human right [23, 27]. This could be partnered with what the United Nations High Commissioner for Human Rights and the WHO Human Right declaration on mental health states, that "*there is a right to be treated with dignity as a human being, that there is the right of everyone to enjoy the highest attainable standard of physical and mental health and the right to have access to psychosocial services and psychosocial intervention in the event of sickness.*" [28] A WHO Resource Book on Mental Health, Human Rights and Legislation and a number of tools (e.g. checklist, training exercises) have been developed, in order to assist countries in reviewing and assessing the comprehensiveness and adequacy of their existing law, to increase people's skills in the area of mental health, human

rights and legislation and to help them in the process of drafting new laws, when necessary. [29,30,31]. These strategies could be extended to psycho-oncology, moving forward from declaration to action in a more structured way. Similar arguments can be done with respect to the Union for International Cancer Control (UICC) that has endorsed the IPOS Standards and recognizing Distress as the 6th Vital Sign; added a specific aim (Target 8) of effective pain control and distress management services to be universally available (UICC World Cancer Declaration 2013); and claimed that it is necessary to promote and support national capacity in order to "*increase investment in basic, clinical and implementation research across fields and disciplines including psycho-oncology, behavioural medicine and survivorship, and make specific efforts to accelerate the translation of research findings into clinical practice*" [32]. Finally, it is increasingly incumbent on POS to challenge the prevailing political discourse of neoliberal rhetoric that is used so often to justify cuts to health services funding and care provision. All to often this is more ideological than it is economic necessity. Advocacy for sustaining and improving care needs to be part of the POS skills set.

However, if this can be important as at an international level, more effort is needed at national level. Without strong coalitions with oncology societies, better national research initiatives, cancer plans and patient advocacy movements, it is difficult that initiatives planned just at an international level can have an impact on national governments, with the risk of leaving the situation of psycho-oncology fragmented in many countries. For example, the European Union Council Conclusions on reducing the burden of cancer [33] has produced in 2008 a document that was signed by the 27 EU Member-States recognizing the important role of psychosocial oncology in cancer stating that '*to attain optimal results, a patient-centred comprehensive interdisciplinary approach and optimal psychosocial care should be implemented in routine cancer care, rehabilitation and post-treatment follow-up for all cancers'* (par. 5), with an open invitation to all EU member states '*to take into account the psychosocial needs of patients and improve the quality of life for cancer patients through support, rehabilitation and palliative care'* (par.19). From our results, however, it seems that these indications have not been respected in the same way in the single countries, and that, in spite of the efforts of the national POS, many countries in Europe are struggling with significant problems.

There are significant limitations in this survey. Because of its descriptive nature, more specific information about the single characteristic of psychosocial oncology in the single countries and more sophisticated statistical analysis are not allowed. Also the participating societies of the Federation reached an agreement in creating a general questionnaire, while more questions and topics could have been better operationalized by using a more structured (e.g. Likert-scales) questionnaire. This has been considered, however, as a further step for the future. The results reported are also based on information provided by the country POS referents and whilst we have endeavoured to be accurate in the description derived from the survey, possible inaccuracies may be present. Also, changes can be determined in the last years after the survey was conducted.

In conclusion, although the survey contains non-negligible limitations, the results depict some important aspects on current status of psycho-social service in countries around the world where established POS exist. Likewise what described in several papers relative to cancer care in general (e.g. access to public health and medical services, shortages of specialist staff, increased demand for services and lack of knowledge about cancer patients' problems) [34,35,36,37,38], the data regarding psychosocial care indicate the need to work more closely together at national and international levels to defend and to make mandatory a true patient-centred comprehensive interdisciplinary approach and optimal and routine psychosocial care in cancer settings.

Acknowledgements: All the members of the single POS are acknowledged for their contribution to the development of psycho-oncology and their commitment.

Legenda: Psycho-oncology societies, currently (2015) members of the IPOS Federation, by areas of the world: **Africa**: Psycho-oncology Society of Nigeria (POSON); **North America**: American Psychosocial Oncology Society (APOS), Canadian Association of Psychosocial Oncology (CAPO). **South America**: Brazilian Psycho-Oncology Society (SBPO). **Europe**: Austrian Platform of Psycho-oncology (ÖPPO), British Psychosocial Oncology Society (BPOS), Bulgarian Society of Psycho-Oncology (BAPO)*, Dutch Society of Psychosocial Oncology (NVPO), French Society of Psycho-Oncology (SFPO) , German Association of Psycho-Social Oncology (DAPO) , Hellenic Society of Psychosocial Oncology (HSPO, Greece) , Hungarian Psycho-Oncology Society (MPOT) ; Italian Society of Psycho-Oncology (SIPO), Lithuania Association of Psychosocial Oncology (POA, Lithuania), Polish Psycho-oncology Society (PPOS), Portuguese Academy of Psycho-Oncology (APPO), Portuguese Psycho-Oncology Society (SPPO) , Romanian Association of Psycho-Oncology (ARPO) , Slovenian Society of Psycho-Oncology; Spanish Psycho-Oncology Society (SEPO) , Swedish Psycho-Oncology Society (SWEDPOS), Swiss Society of Psycho-Oncology (SGPO). **East Asia**: Chinese Psycho-Oncology Society (CPOS), Japan Psycho-Oncology Society (JPOS) , Korean Society Psycho-Oncology, Taiwanese Psycho-Oncology Society (TPOS). **Australia/New Zealand**: Australian Psychosocial Oncology Society (OZPOS) and Psycho-oncology Co-operative Research Group (PoCoG, Australia) , Psycho-Social Oncology New Zealand (PONZ). **Middle East**: Israel Psycho-Oncology Society (IPSO); Turkish Psychosocial Oncology Association (PSOD)

* The Bulgarian Society of Psycho-Oncology became part of the Federation in 2015. There are also countries that have societies in a developing phase, including the Irish Society of Psycho-Oncology, the Russian Society of Psycho-Oncology, the Psycho-Oncology Society in Kenya and the society of Psycho-Oncology in South Africa, where, at the moment, the South African Oncology Social Work Association (SAOSWA)

Table 1. Federated Psycho-Oncology societies and main characteristics

Area of the world and country	Year of foundation and website	N. members	Support from the government	Link with academic institutions	Link with other professional societies (e.g. nursing, oncology, palliative care)	Coverage of PO by NHS or insurance	Level of development of PO in the country (see appendix for legenda
Africa							
Nigeria	2009 www.posononline.com	100	N	Y	N		3a
Asia							
China	2006	425	Y	Y	Y	Y	3b
Japan	1986 http://www.jpos-society.org/	1683	Y	N	Y	Y	4b
Korea	2005	80	N	N	N	N	3a
Taiwan	2009 www.tpos-society.org/	167	Y	Y	Y	Y	4a
Australia							
Australia	2005 www.pocog.org.au	1240	Y	Y	Y	Y	4b
New Zealand	2001 www.ponz.org.nz	35	Y	Y	N	N	3b
Europe							
Austria	2003 www.oeppo.com	80	N	Y	Y	Y	4a
France	1982 www.sfpo.fr	100	N	N	Y	Y	4a
Germany	1983 www.dapo-ev.de	529	Y	Y	Y	NR	4b
Italy	1985 www.siponazionale.it	732	N	Y	Y	Y	4a
Lithuania	2007 www.POA.lt	40	N	Y	Y	Y/N	3b
Netherlands	1993 www.nvpo.nl	450	N	Y	Y	Y	4a
Poland	1993 www.ptpo.org.pl	200	Y	--	Y	Y	4a
Portugal	1995 1999 www.appo.pt	71 100	N N	Y N	Y N	Y	3b/4a
Romania	2002 www.arpo.org	80	N	Y	Y	Y/N	3a
Slovenia	2011	15	Y	Y	Y	Y	3a
Spain	2002 www.sepo.es	100	N	N	N		3a
Sweden	2007 www.swedpos.se	130	N	N	Y	Y	3b
Switzerland	2003 www.psychoonkologie.c	220	N	Y	Y	Y	4a

	h						
UK	1983 http://www.bpos.org	60	N	N	N	Y	4a
Middle East							
Israel	1992	170	N	Y	Y		4a
North America							
Canada	1987 www.capo.ca	300	Y	Y	N	Y	4a
USA	1986 www.apos-society.org	450	Y	Y	Y	Y/N	4a
South America							
Brazil	1994 www.sbpo.org.br	330	N	N	Y	Y	3a

Legenda: Y=Yes; N=No; Y/N, not completely covered by the national health system or partially covered; NR=Not reported

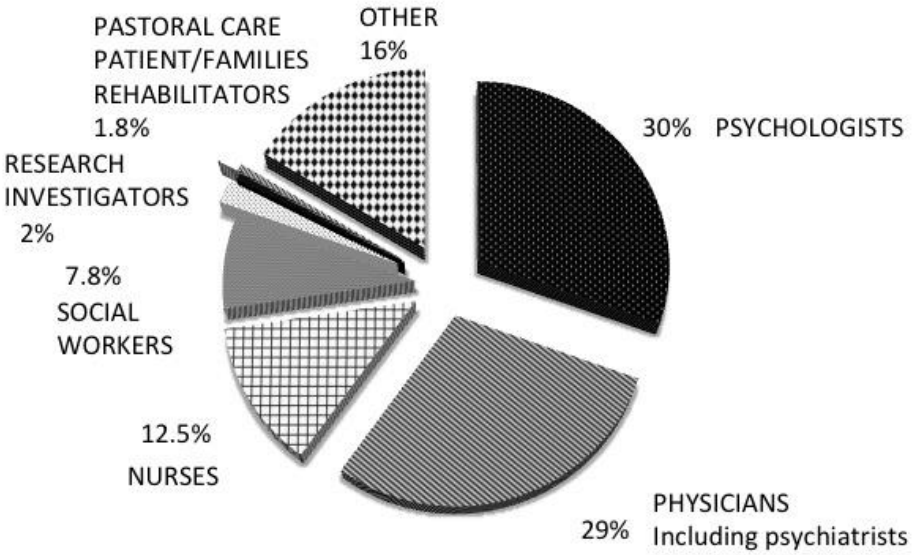

Fig. 2. Roles and professions of the members of the 25 POS of the Federation

Table 2. Main problems to cope with as reported by the Federated POS

1. Lack of resources and funding (including no government support)
2. Problems with the national health care system (e.g. PO either not taken into account in National Cancer Plans, or when part of NCP, but not considered within the specialties that are part the Essential Level of Care)
3. Difficult Implementation of national homogenous guidelines in the area of psycho-oncology
4. PO not recognized as a speciality (ministerial level)
5. Lack of psychosocial oncology services for cancer patients and families in small towns or rural and remote areas (psycho-oncology mostly active in highly specialized cancer centers or university centers)
6. Problems of dissemination of psycho-oncology in a multi-ethnic and multi-cultural country with some ethnic minorities have their own language and culture
7. Small number of mental health professionals (e.g. psychologists, psychiatrists) trained in psycho-oncology and no contract for them within the health care system
8. Stigma about mental health issues

Appendix 1. Summary of the main area investigated by the questionnaire

A) **Society information**

- Name of the society:
- Year of foundation:
- Number of Members regularly registered (approximately):
- Society Website URL (if existent):
- Name of the current President: (appointed year: -)
- Is there a regular conference? – how often? :
- What are the existing communication methods among members? (check what applies)
  - ☐ Journal (Please provide name and website link:)
  - ☐ Newsletter
  - ☐ Email list
  - ☐ Social network service (e.g. Facebook) (specify:)
  - ☐ Others (specify:)

- Composition of members of your society
  - 1) Advanced practice nurse: %
  - 2) Registered nurse : %
  - 3) Patients and family : %
  - 4) Physician (other than psychiatrist): %
  - 5) Psychiatrist : %
  - 6) Psychologist : %
  - 7) Social worker : %
  - 8) Others (please specify) : % ( )
  - Others (please specify) : % ( )

B) **Society information**

Organization

1. Committees / Subgroups (Please list all committees, special interest groups, and other subgroups of the society; e.g. executive board, publication committee, pediatric workgroup, etc...)
2. Is there any support from (or link to) the government? If yes, please describe.
   Yes / No
3. Is there any link to academic institutions? If yes, please describe.
   Yes / No
4. Is there any partnership with other professional societies (e.g. nursing, oncology, palliative care...)? If yes, please describe.
   Yes / No
5. Please describe if there is any other information (characteristics of your society) you want to add.

Activities

1. Please list a few major ongoing projects / activities of the society
2. What are the facing problems / challenges of the society?
3. Are there any internationally collaborative projects?
4. Is your society willing to mentor, to be mentored, or to be partnered with other federation societies? If so, please describe possible area of collaboration.
5. Is there anything your society wants IPOS or IPOS Federation to do to help promoting the activities of your society?

Health care information

Describe if there is any characteristic of your community (health care system, culture, etc.) that may influence (benefit or impede) psycho-social care of cancer patients? (e.g. National universal health insurance coverage, lack of resources, etc) Please include comments on whether psycho-oncology care is reimbursed (covered) in your health-care system.

Situation of Psycho-social oncology in the country

Please circle the level (number) that best describes the situation of psychosocial oncology in your country.

Level	Description
1	No known psycho-social oncology care activity Unable to identify any psycho-social care activity in the country, although there may be chances that current work has been unrecognized.
2	Capacity building activity There is evidence of wide-ranging initiatives designed to create the organizational, workforce and policy capacity for psychosocial oncology care services to develop, though no service has yet been established. The developmental activities include: attendance at, or organization of, key conferences; personnel undertaking external training in psycho-social oncology care; lobbying of policy-makers and ministries of health; and incipient service development.
3a	Isolated care provision The country is characterized by: the development of psychosocial oncology care activism that is patchy in scope and not well supported; sourcing of funding that is often heavily donor-dependent; limited availability of care.
3b	Generalized care provision The countries is characterized by: the development of psychosocial oncology care activism in a number of locations with the growth of local support in those areas; multiple sources of funding; the availability of care; a number of psychosocial oncology care services from a community of providers that are independent of the healthcare system; and the provision of some training and education initiatives.
4a	Preliminary integration into mainstream service provision The countries is characterized by: the development of a critical mass of psychosocial oncology care activism in a number of locations; a variety of psychosocial oncology care providers and types of services; awareness on the part of health professionals and local communities; the availability of psychosocial oncology service; limited impact of psychosocial oncology service care upon policy; the provision of a substantial number of training and education initiatives by a range of organizations.
4b	Advanced integration into mainstream service provision The country is characterized by: the development of a critical mass of psychosocial oncology care activism in a wide range of locations; comprehensive provision of care by multiple service providers; broad awareness of psychosocial oncology care on the part of health professionals, local communities and society in general; unrestricted availability of multiple aspects of psychosocial oncology care; substantial impact of psychosocial oncology care upon policy, in particular upon public health policy; the development of recognized education centers; academic links forged with universities.

Appendix 2.

The paper has been co-authored by all the members that participated in the survey as referents/presidents of the national POS, namely

Judith Alder (judithalder1@gmail.com), Switzerland
Elisabeth Andtritsch (Elisabeth.Andritsch@klinikum-graz.at), Austria
Antonio Barbosa (abarbosa@netcabo.pt), Portugal
Joan Bottorff (joan.bottorff@ubc.ca), Canada
Giedre Bulotiene (giedre.bulotiene@vuoi.lt), Lithuania
Phillys Butow (phyllisb@psych.usyd.edu.au), Australia
Miri Cohen (mcohen2@univ.haifa.ac.il), Israel
Anna Costantini (annacostantini@alice.it), Italy
Sara Dauchy (Sarah.DAUCHY@gustaveroussy.fr), France
Csaba L. Dégi (csabadegi@gmail.com), Romania
Jurama Ribeiro de Oliveira (presidente@sbpo.org.br), Brazil
Krystyna de Walden-Galuszko (galuszko@ptpo.org.pl), Poland
Haryana Dhillon (haryana.dhillon@sydney.edu.au), Australia
Chun-Kai Fang (chunkai.fang0415@gmail.com), Taiwan
Michelle Cororve Fingeret (MCFinger@mdanderson.org), USA
Francisco Luis Gil (fgil@iconcologia.net), Spain
Patrik Göransson (ordforande@swedpos.se), Sweden
Josette Hoekstra Weebers (.Hoekstra@iknl.nl), The Netherlands
Clare Louise Manicom (Clare.Manicom@cancercare.co.za), South Africa
Deborah McLeod (DeborahL.McLeod@cdha.nshealth.ca), Canada
Lúcia M. Silva Monteiro (lmonteiro@ipolisboa.min-saude.pt), Portugal
Jong-Heun Kim (psy@ncc.re.kr), Korea
Hazel Neser, (hazel.neser@otago.ac.nz), New Zealand
Eisuke Matsushima (em.lppm@tmd.ac.jp), Japan
William F. Pirl (WPIRL@PARTNERS.ORG), USA
Melanie Price (melanie.price@sydney.edu.au), Australia
Laura Monica Radu (ml2radu@yahoo.com), Romania
Thomas Schopperth, (tschopperth@krebsgesellschaft-rlp.de), Germany
Andrea Schumacher (Andrea.Schumacher@ukmuenster.de), Germany
Anja Simonič (anja.simonic@klinika-golnik.si), Slovenia
Lili Tang (tanglili2005@hotmail.com), China

References

1 Global Burden of Disease Cancer Collaboration: The Global Burden of Cancer 2013. JAMA Oncol. 2015 July 1; 1(4): 505–527.

2 World Health Organization (WHO): Cancer control: knowledge into action. WHO, Geneva, 2015, http://www.who.int/cancer/modules/en/

3 Stewart B.W., Wild C.P. (Eds.): World Cancer Report 2014. International Agency for Research on Cancer, World Health Organization (WHO), Geneva, 2014

4 Gelband H, Sankaranarayanan R, Gauvreau CL, Horton S, Anderson BO, Bray F, Cleary J, Dare AJ, Denny L, Gospodarowicz MK, Gupta S, Howard SC, Jaffray DA, Knaul F, Levin C, Rabeneck L, Rajaraman P, Sullivan T, Trimble EL, Jha P; Disease Control Priorities-3 Cancer Author Group. Costs, affordability, and feasibility of an essential package of cancer control interventions in low-income and middle-income countries: key messages from Disease Control Priorities, 3rd edition. Lancet. 2015 Nov 10. pii: S0140-6736(15)00755-2

5 Mitchell AJ, Chan M, Bhatti H, Halton M, Grassi L, Johansen C, Meader N.: Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. Lancet Oncol. 2011 Feb;12(2):160-74.

6 Carlson LE, Waller A, Mitchell AJ.: Screening for distress and unmet needs in patients with cancer: review and recommendations J Clin Oncol. 2012 Apr 10;30(11):1160-77.

7 Swash B, Hulbert-Williams N, Bramwell R.: Unmet psychosocial needs in haematological cancer: a systematic review. Support Care Cancer. 2014 Apr;22(4):1131-41

8 Lam WWT, Chan M, Hung WK, O A, Ho S. Bonanno G, Fielding R. Resilience to distress among Chinese women diagnosed with breast cancer, Psycho-Oncology, 2010, 19 1044-1051

9 Bidstrup PE, Christensen J, Goldschmidt-Merz B, Rottmann N, Oksbjerg-Falton S, Johanssen C. Trajectories of distress, anxiety and depression among women with breast cancer: looking beyond the mean. Acta Oncol, 2015, 54, 5 DOI: 10.3109/0284186X.2014.1002571

10 Lam WWT, Yee TS, Bonanno GA, Mancini AD, Fielding R. Distress trajectories during the first year following diagnosis of breast cancer in relation to 6-years survivorship. Psycho-Oncology, 2011, 21, 90-99

11 Giese-Davis J, Collie K, Rancourt KM, Neri E, Kraemer HC, Spiegel D.: Decrease in depression symptoms is associated with longer survival in patients with metastatic breast cancer: a secondary analysis. J Clin Oncol. 2011;29(4):413-20.

12 Kanani R, Davies EA, Hanchett N, Jack RH. The association of mood disorders with breast cancer survival: an investigation of linked cancer registration and hospital admission data for South East England. Psychooncology. 2016;25(1):19-27

13 Koch U.: IPOS Sutherland Memorial Lecture: psycho-oncology and health care research. Psychooncology 2008;17(6):533-537.

14 Jacobsen PB, Wagner LI. A new quality standard: the integration of psychosocial care into routine cancer care. J Clin Oncol. 2012;30(11):1154-9

15 Keller M, Weis J, Schumacher A, Griessmeier B. Psycho-oncology in a united Europe--changes and challenges. Crit Rev Oncol Hematol. 2003;45(1):109-17.

16 Travado L., Reis J., Watson M., Borras J.: Psychosocial Oncology Care Resources in Europe: a study under the European Partnership on Action Against Cancer [EPAAC]. Psycho-Oncology (in press)

17 Mehnert A, Koch U. Psychosocial care of cancer patients—international differences in definition, healthcare structures, and therapeutic approaches. Support Care Cancer 2005;13:579–588.

18 International Psycho-Oncology Society (IPSO: Federation of Psycho-Oncology Societies http://www.ipos-society.org/about-ipos/ipos-federation/

19 Grassi L, Watson M; IPOS Federation of Psycho-Oncology Societies' co-authors. Psychosocial care in cancer: an overview of psychosocial programmes and national cancer plans of countries within the International Federation of Psycho-Oncology Societies. Psychooncology. 2012;21(10):1027-33.

20 Worldwide Palliative Care Alliance. Global Atlas of Palliative Care at the End of Life. 2014 [URL: http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf] (last accessed 2015-Dec-21)

21 Coyne JC, Stefanek M, Palmer SC. Psychotherapy and survival in cancer: the conflict between hope and evidence. Psychological Bulletin, 2007, 133, 3, 367-394.

22 Travado L., Breitbart W., Patenaude A., Baider L., Grassi L., Fujisawa D., Connor S., Fingeret M.: 2015 President's plenary international psycho-oncology society: Psychosocial Care as a Human Rights Issue - Challenges and Opportunities. Psycho-Oncology (in press)

23 Breitbart W, Bultz BD, Dunn J, Grassi L, Watson M. 2012 President's Plenary International Psycho-Oncology Society: future directions in psycho-oncology. Psychooncology. 2013;22(7):1439-43.

24 Bultz BD, Cummings GG, Grassi L, Travado L, Hoekstra-Weebers J, Watson M.: 2013 President's Plenary International Psycho-oncology Society: embracing the IPOS standards as a means of enhancing comprehensive cancer care. Psychooncology. 2014;23(9):1073-8

25 Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. Journal of Pain and Symptom Management 2013;45(6):1094-106

26 World Health Organization (WHO): Palliative Care. Fact sheet N°402 World Health Organization (WHO), Geneva, 2015. www.who.int/mediacentre/factsheets/fs402/en/

27 Miranda J, McGuire TG, Williams DR, Wang P.: Mental health in the context of health disparities. Am J Psychiatry. 2008;165(9):1102-8.

28 Office of the United Nations High Commissioner for Human Rights / World Health Organization (WHO): The Right to Health. Fact Sheet No. 31, United Nations, Geneva, 2008

29 World Health Organization (WHO): WHO Resource Book on Mental Health, Human Rights and Legislation. World Health Organization (WHO), Geneva, 2004

30 Rosenthal E., Sundram C.J.: The Role of International Human Rights in National Mental Health Legislation. World Health Organization (WHO); Geneva, 2004

31 World Health Organization (WHO): Health and human rights Fact sheet N°323. World Health Organization (WHO), Geneva, 2015. www.who.int/mediacentre/factsheets/fs323/en/

32 Union for International Cancer Control (UICC): World Cancer Declaration 2013. www.uicc.org/sites/main/files/private/131119_UICC_WorldCancerDeclaration_2013_1.pdf

33 European Union: Council Conclusions on reducing the burden of cancer. www.eu2008.si/en/News_and_Documents/Council_Conclusions/June/0609_EPSCO-cancer.pdf - Luxembourg, 10 June 2008.

34 Harford JB.: Barriers to overcome for effective cancer control in Africa. Lancet Oncol. 2015;16(8):e385-93

35 Steinberg ML: Inequity in cancer care: explanations and solutions for disparity. Semin Radiat Oncol. 2008;18(3):161-7

36 Goss E, Lopez AM, Brown CL, Wollins DS, Brawley OW, Raghavan D. American society of clinical oncology policy statement: disparities in cancer care. J Clin Oncol, 2009; 27(17):2881-5

37 Munro AJ. Comparative cancer survival in European countries. Br Med Bull. 2014;110(1):5-22.

38 Ahmed S, Shahid RK.: Disparity in cancer care: a Canadian perspective. Curr Oncol. 2012;19(6):e376-82